

Position Statement:

Self Determination

“Self Determination is when we as advocates know ourselves, make our own decisions and solve our own problems”

~Delaware People First

Background:

“Self-determination” is such an integral part of one’s adulthood that many people would struggle to recognize the term, define it or understand it. Decisions such as what time to eat dinner, what color curtains you want in your bedroom or where you go to church are understood to be nothing more than trivial “everyday decisions” that all adults make. However, people with disabilities frequently have much less latitude in making such “everyday decisions.” People with disabilities frequently live lives that are “funding-determined,” “aide-determined,” “staff-determined,” or “parent-determined.” This is not right.

When an adult shops for food he or she is able to determine for themselves what type/s of food to purchase. However, many people with developmental disabilities live lives that do not reflect this simple example of self-determination.

Having a developmental, mental or physical disability does not mean that someone should have to forfeit decisions about where they live, what type of job they have or what activities they do for leisure. This position statement underlines and explains the Delaware Developmental Disabilities Council’s position on self-determination: Everyone deserves the right to live life in a self-determined manner with as much control over personal affairs as possible. Promoting self-determination is best practice for people, families and communities.

What is Self-Determination?

“Self-determination” is when a person has the attitudes, ability and control to make their own life decisions. “The goal of 'self-determination' efforts is to create meaningful, culturally appropriate lives [for all people] embedded in our communities and suffused with real relationships.” Transitioning people with developmental, mental or physical disabilities from institutions to community settings and given them real control over their lives is a foundational aim of the self-determination movement. (*Center for Self Determination; Policy Analysis of New Jersey's Self Determination Effort*)

What is the Problem?

Due to physical, mental or developmental disabilities, certain people are not being afforded the opportunity to live self-determined lives. One's abilities or disabilities have nothing to do with the right that all people have to live self-determined lives; yet, these disabilities are frequently used as a rationale to justify the denial of self-determination to certain people. The traditional case-management system is broken as it fails to promote self-determination on the part of the client.

Here is what a self-determined person looks like:

-Daily Life

A self-determined person:

- Decides what he or she wants to eat
- Decides when he or she wants to eat
- Decides when to wake up

-Home Life

A self-determined person:

- Decides where he or she wants to live.
- Is allowed to decorate his or her dwelling place.
- Is allowed to self-schedule leisure activities.

-Work Life

A self-determined person:

- Is able to self-select a job from a range of opportunities.
- Request supports to allow workplace success.
- Has access to transportation to and from work.

-Public Life

A self-determined person:

- Is kept current on legislation that affects his or her life
- Attends hearings about bills

- Self-advocacy and civic engagement are encouraged
- Testifies at committee meetings

-Medical

A self-determined person:

- Knows what medication/s he or she is prescribed
- Knows why they are prescribed a medication
- Knows all the side-effects of a medication
- Is able to refuse a medication or treatment
- Is treated like a customer capable of making informed care choices
- Understands medical procedures before giving "informed consent"

-Education

- A self-determined person:

- Is an integral part of his or her IEP team
- Takes part in course selections
- Guides transition planning

Policy Recommendations:

-State agencies and service providers who work with people with developmental disabilities should be subject to yearly audits by an independent advocacy group. These audits should evaluate the organization's policies and procedures to assess the extent to which the organization is promoting self-determination in the lives of its clients. These results should be posted online and submitted to the Delaware Developmental Disabilities Council (DDC) and the Governor's Advisory Council on Exceptional Citizens (GACEC). Future funding decisions and contract awards should include consideration of a provider's "self-determination" audit.

-State agencies and service providers who work with people with developmental disabilities should receive yearly training in self-determination. These trainings should model self-determination and be led by people with developmental disabilities. The DDC and GACEC are available to provide technical assistance in the development of these training sessions.

-DHSS should hire and train a "self-determination advocate." This advocate would be available to assist adults with developmental disabilities determine which areas of life in which they are not self-determined. The advocate and the client could then approach the client's service providers with recommendations on how to increase the client's level of self-determination in daily life decisions. This advocate should follow the principles of "self-directed care" and be independent of case managers and financial intermediaries.

-DHSS should create a dispute resolution procedure to resolve disputes between clients and service providers when client requests or advocate recommendations relating to self-determination are not followed. This process can be conducted by a DHSS Ombudsman and all proceedings should be included in the involved service provider's yearly "self-determination" audit.

- Existing data gathering tools such as "client satisfaction surveys" should be amended to include a category for "self-determination." This confidential information will allow "self-determination advocates" to proactively seek out clients of a provider who is receiving low marks in the "promotion of self-determination" category.

-The intent of the "Money Follows the Person" provision in the Olmstead decision is to shift people from institutional settings to more natural community settings. There is no point in moving people to community settings if that setting does not allow for people to live self-determined lives. Community settings are a natural place to practice self-determination because by definition they are community based which allows for more access to jobs, programs and leisure activities.

-A person with disabilities is more likely to have good care outcomes and higher program participation rates when they are given the chance to make self-directed care (SDC) decisions regarding their medical care. Giving a person with the disabilities the dignity to make informed care decisions is morally correct and will create long-term health and

cost savings. The State of Florida transitioned a study group of people with developmental disabilities from the fee-for-service (FFS) model to the “self-directed care” model and saw the following results when SDC participants were compared to a FFS participants: 1) SDC participants had lower rates of crisis stabilization; 2) higher customer satisfaction; 3) higher utilization of medial assessments, psychotherapy and supported employment services and 4) budget neutrality by the second year of the program. Self-directed care is cost-effective and benefits the client (*Center for Mental Health Services Research and Policy; University of Illinois*).

-Wherever possible, State agencies and private service providers should make deliberate efforts to help people with developmental disabilities find their “voice.” Simple activities such as “open mic” or client led discussions help people with developmental disabilities develop the communication and advocacy skills needed to be self-determined.

Path forward:

Self-determination is a right for all people. When decisions about a person with developmental disabilities are made, the essential question that should be asked is: Was this decision made by the person in question or someone else (teacher, aide, parent or service provider)? People with developmental disabilities have the right to live self-determined lives. Self-advocates are more likely to have positive health and life outcomes and self-advocacy should be encouraged.

If adults with developmental disabilities continue to have life decisions made to or for them, they will gradually lose their adulthood. This lack of self-determination is unacceptable and not what any parent would want for their child.

Self-determination is best practice for all organizations, companies and communities. Self-advocates should be leading the self-determination movement. The DDC’s role is to educate and advocate for policies that increase one’s ability to live a self-determined life.

For more resources please contact the DDC at:

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